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THE ADVANCE DIRECTIVE REGISTRY OR LOCKBOX: A MODEL PROPOSAL AND CALL TO LEGISLATIVE ACTION

*Joseph Karl Grant**

I. INTRODUCTION

Have you ever had occasion to hide, misplace, or lose an important legal document, one which has a major impact on your legal rights, at moment when you needed it the most? A number of us have probably been in this situation far too many times to recall. In most cases, things seem to work out fine and we end up stumbling over the document we were looking for in the strangest of locations, probably when we are not looking. Let me pose a second question. How many of you have dreamed or wished for a magical place where you could store all of your legal documents? In this magical place, you would have the ability to store important legal documents that have an impact on and affect your legal rights. Moreover, you would have the ability to retrieve them instantly at that critical moment when you need that particular legal document the most. Personally, I have dreamed of this mythical and magical repository for most of my adult life. The person who invents this magical portal where one could place the important legal documents and papers that govern life, will probably end up as one of the richest people to walk the earth.

In our everyday lives, some legal documents and papers are more critical than others from the perspective of personal health and integrity. Take for example your living will or durable health care power of attorney. If you are involved in a car accident and rendered unconscious, you

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obviously no longer have the capacity to provide informed consent to medical treatment; someone will need to make decisions for you. God forbid that your family or loved ones cannot find your durable health care power of attorney in the maze of documents in your home! You may awaken to a world where you discover that health care providers have rendered medical treatment or performed procedures that run counter to your expressed personal wishes.

Let us make the stakes a little higher. Assume that over the years you have been telling your closest family members that you would not want to be placed on life support if you ever became afflicted with a medical condition placing you in a permanent vegetative state. You turn to your trusted attorney who prepares a legally valid and binding living will or advance directive according to the laws of your jurisdiction. Further assume that due to some hidden and latent medical condition which you and your doctors were totally unaware of, you are suddenly stricken while exercising at the gym and fall into a coma that deprives your brain of oxygen for several moments. As a result you are now in a permanent vegetative state. Health care providers want to place you on life support to preserve your life. Your family makes your wishes known. Unfortunately, your family cannot track down your attorney, who happens to be on a vacation of a lifetime in Bali and Fiji and who, selfishly for you at that moment, has severed all modes of communications with her office. Even worse, in the jungle of legal documents and papers in your home, your living will is hidden and tucked away between pages 50 and 51 of your favorite hardbound copy of Sun Tzu's *The Art of War*. This is not the usual place for you to store such an important document, but you accidentally left it there while leafing through the *Art of War* used your living will as bookmark after reading it late one evening. The bottom line is this: at the moment you need your living will the most, it is nowhere to be found. This situation could easily happen to you, or to anyone else.

In times of need, what portal or place could we go to easily retrieve a person's advance directives when we have need to employ and use them? A handful of states have come up with a solution. Nevada,¹ Washington,² and Vermont³ now have legislation in place that allow citizens of those states to electronically store their advance directives on the internet – in an electronic lockbox or portal of sorts. These states have addressed a critical need of their citizens: the need to have their advance directives accessible and readily available to health care providers so that their intent and wishes will be honored.

1. NEV. REV. STAT. §§ 449.900 – 449.965 (2010).

2. R.C.W §§ 70.122.120 - 70.122.140 (2011).

3. 18 V.S.A. Chapter 231 (§§ 9700 – 9720). The Vermont Department of Health has also adopted rules and regulations to aid in the implementation of the Vermont's Advance Directive Registry. These regulations may be viewed and accessed at http://www.healthvermont.gov/regs/ad/Advance_Directives_Rules.pdf (last visited April 13, 2011).

This Article advocates that other states follow the lead of Nevada, Washington, and Vermont by adopting similar legislation and embracing digital or electronic technology by creating Internet "lockboxes," registries, or portals where citizens can store their advance directives and where health care providers can access these advance directives in the most pressing and critical situations. Part II of this Article examines the rationale and need driving the creation of digital or electronic registries. Part III of lays out a model for the movement toward an advance directive for health care registry. Specifically, Part III examines some of the pitfalls and shortcomings in existing legislation in Nevada, Washington, and Vermont and sets forth model legislation that could be adopted by states wishing to legislatively create an advance directive for health care registry. Part IV explores who could administer an advance directive for health care registry in the states that decide to adopt the model legislation. Part V addresses the mechanisms and means to create the website or portal. Part VI explores the cost and expenses involved in building and maintaining the website or portal. Part VII explores the demographic issue, namely who will use and benefit from an advance directives for health care registry.

II. RATIONALE DRIVING THE CREATION OF AN ADVANCE DIRECTIVES FOR HEALTH CARE REGISTRY

There are a number of reasons to create an advance directives for health care registry. First, an advance directives for health care registry would give registrants the peace of mind in knowing that their health care choices are secure and will be available to their family members and physicians when they fall ill.⁴ The registrant will have "peace of mind" knowing that their advance directive is secure and incapable of being physically lost or misplaced.⁵ Second, the registrant's intentions and wishes regarding health care decisions will be known to their family members and doctors.⁶ Metaphorically, the registrant will be enabled and empowered to "speak" to their family members and doctors and convey their "personal philosophy and help them make the decisions [they] want without feeling guilt or remorse."⁷ In a sense, the registrant will have the ability to have their "say" in their own health care decisions although they might not be able to speak or communicate. Presumptively, health care providers assume that their medical treatment, which could include life-sustaining treatment, unless they are affirmatively told otherwise. Finally, the registrant will benefit from the twenty-four hour secure access hospitals and healthcare providers

4. The Vermont Department of Health's website lists a number of benefits associated with an advance directives registry. See generally Vermont Advance Directives Registry, VERMONT DEPARTMENT OF HEALTH, <http://healthvermont.gov/vadr/index.aspx#benefits> (last visited February 20, 2011).

5. *Id.*

6. *Id.*

7. *Id.*

will have to their advance directives.⁸ We live in a world of documents—it must be underscored how important it is place documents in a safe and secure location so that they may be easily retrieved when needed most. We all know how easy it is to misplace or lose an important document.

III. MOVEMENT TOWARDS A MODEL ADVANCE DIRECTIVES FOR HEALTH CARE REGISTRY

A. Pitfalls and Shortcomings in the Current Advance Directive Registry Acts in Nevada, Washington, and Vermont

Although a groundbreaking piece of legislation, several drafting considerations or "tweaks" would aid in improving the Nevada, Washington, and Vermont advance directives registries. First, definitions of key and integral terms used throughout the act should be collected together and contained in one cohesive section. Second, a statement of purpose and scope is necessary in order to facilitate judicial interpretation of the legislative scheme. Third, HIPPA and privacy concerns should be clearly addressed in any proposed statutory scheme. Fourth, protocols allowing for update and modification of information contained in the database need to be made clear. Fifth, procedures to revoke advance directives on the database need to be made clear. Finally, procedures allowing the removal of lapsed advance directives due to death should clearly be delineated.

B. A Call to Action: A Proposal for a Model Advance Directives for Health Care Registry

The adoption of advance directive for health care registries in Nevada, Washington, and Vermont reflects the need to reform the law to facilitate memorialization and access to advance directives. A model or systematic approach is necessary for other states and jurisdictions wishing to follow the lead of Nevada, Washington, and Vermont. Undoubtedly, a uniform or model approach to create an advance directives for health care registry or lockbox would be timely and critical given the state of current technology.

The proposed model advance directives for health care registry is provided below and consists of three (3) parts:

PART I

1-101. Short Title. *This Act shall be known and may cited as the Advance Directives For Health Care Registry Act.*

1-102. Legislative Findings. *The legislature finds that effective communication between patients, their families, and their care givers regarding their wishes if they*

8. *Id.*

become incapacitated results in health care decisions that are more respectful of patients' desires. Whether the communication is for end-of-life planning or planning to sustain life, the state must respect those wishes and support efforts to facilitate such communications and to make that information available when it is needed.

It is the intent of the legislature to establish an electronic registry to improve access to health care decision-making documents. The registry would support, not supplant, the current systems for advance directives by improving access to these documents. It is the legislature's intent that the registry would be consulted by health care providers in every instance where there may be a question about the patient's wishes for periods of incapacity and the existence of a document that may clarify a patient's intentions unless the circumstances are such that consulting the registry would compromise the emergency care of the patient.⁹

1-103. Purposes; Rules of Construction.

1. *This Act shall be liberally construed and applied to promote the underlying purposes and policies.*
2. *The underlying purposes and policies of this Act are:*
 - (a) *To facilitate the use and enforcement of electronic and other emerging technology in memorializing the intent and wishes of individuals, as expressed in their advance directives, in communicating their advance directives regarding health care decisions in this state;*
 - (b) *To simplify and clarify the law concerning health care decisions in this state;*
 - (c) *To discover and make effective the intent of an individual in communicating their advance directives regarding health care decisions to health care providers in this state; and*
 - (d) *To promote a speedy and efficient system for communicating an individual's advance directives regarding health care decisions to health care providers in this state.*

PART II

1-201 General Definitions.

For purposes of this chapter, the following terms shall have the following definitions:

1. *"Advance directive" means an advance directive for health care. The term includes:*
 - (a) *A declaration governing the withholding or withdrawal of life-sustaining treatment;*
 - (b) *A durable power of attorney for health care decisions;*

- (c) A *do-not-resuscitate order* or "DNR order" means a written order directing health care providers not to attempt resuscitation; and
- (d) An *anatomical gift declaration* which directs health care providers the authority to harvest and use a person's organs, tissues, bones, and cartilage.
2. "Agent" means an adult with capacity to whom authority to make health care decisions is delegated under an advance directive, including an alternate agent if the agent is not reasonably available.¹⁰
3. "Capacity" means a person's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision.¹¹
4. "Guardian" means a judicially appointed guardian or conservator having authority to make health care decisions for a person.¹²
5. "Health care" means any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect an individual's physical or mental condition.¹³
6. "Health care decision" means a decision made by a person or the person's agent, guardian, or surrogate, regarding the person's health care, including:
- (a) Selection and discharge of health care providers and institutions;
 - (b) Approval or disapproval of diagnostic tests, surgical procedures, programs of medication, and orders not to resuscitate; and
 - (c) Directions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care.¹⁴
7. "Health care institution" means an institution, facility, or agency licensed, certified, or otherwise authorized or permitted by law to provide health care in the ordinary course of business.¹⁵
8. "Health care provider" means an individual licensed, certified, or otherwise authorized or permitted by law to provide health care in the ordinary course of business.¹⁶
9. "Person" means an individual, age eighteen (18) or older, who possesses capacity.
10. "Reasonably available" means readily able to be contacted without undue effort and willing and able to act in a timely manner considering the urgency of the patient's health-care needs.¹⁷
11. "Registrant" means a person whose advance directive is registered with the

10. VT. STAT. ANN. tit. 18, §9701 (2010).

11. UNIF. HEALTH-CARE DECISIONS ACT § 1(3), 9 U.L.A. 89 (2005).

12. *Id.* § 1(4).

13. *Id.* § 1(5).

14. *Id.* § 1(6).

15. *Id.* § 1(7).

16. *Id.* § 1(8).

17. *Id.* § 1(14).

*Secretary of State.*¹⁸

12. "Registry" means a secure, Internet web-based database created by the Secretary of State to which person's may submit an advance directive that is accessible to the person and agent and, as needed, to health care providers, health care institutions, and the employees thereof.

13. "Secretary" shall mean the Secretary of State [or Secretary of Health].

14. "Surrogate" means a person, other than a patient's agent or guardian, authorized under this Act to make a health care decision for the patient.¹⁹

PART III

1-301. Establishment and Maintenance; Information to be Included in Registry. The Secretary of State shall establish and maintain the Advance Directives for Health Care Registry on his or her Internet website. The Registry must include, without limitation, in a secure portion of the website, an electronic reproduction of each advance directive. The electronic reproduction must be capable of being viewed on the website and downloaded, printed or otherwise retrieved by a person as set forth in §1-302.²⁰

1-302. Registration of Advance Directive: Requirements; Duties of Secretary of State.

1. A person who wishes to register an advance directive must submit to the Secretary of State:

- (a) An application in the form prescribed by the Secretary of State;
- (b) A copy of the advance directive; and
- (c) The fee, if any, established by the Secretary of State pursuant to § 1-301.

2. If the person satisfies the requirements of subsection 1, the Secretary of State shall:

- (a) Make an electronic reproduction of the advance directive and post it to the Registry;
- (b) Assign a registration number and password to the registrant; and
- (c) Provide the registrant with a registration card that includes, without limitation, the name, registration number and password of the registrant.

3. The Secretary of State shall establish procedures for;

- (a) The registration of an advance directive that replaces an advance directive that is posted on the Registry;

18. NEV. REV. STAT. § 449.910 (2010).

19. UNIF. HEALTH-CARE DECISIONS ACT § 1(17).

20. NEV. REV. STAT. § 449.920.

(b) The removal from the Registry of an advance directive that has been revoked following the revocation of the advance directive or the death of the registrant; and

(c) The issuance of a duplicate registration card or the provision of other access to the registrant's registration number and password if a registration card issued pursuant to this section is lost, stolen, destroyed or otherwise unavailable.²¹

1-303. Access to Advance Directive.

1. Except as otherwise provided in this section, the Secretary of State shall not provide access to a registrant's advance directive unless:

(a) The person requesting access provides the registration number and password of the registrant;

(b) The Secretary of State determines that providing access to the advance directive is in the best interest of the registrant;

(c) Access to the advance directive is required pursuant to the lawful order of a court of competent jurisdiction; or

(d) Access to the advance directive is requested by the registrant or his personal representative.

2. A registrant or the personal representative of a registrant may access the registrant's advance directive for any purpose. A provider of health care to the registrant may access the registrant's advance directive only in connection with the provision of health care to the registrant.²²

1-304. Confidentiality and Privacy. In designing the advance directive for health care registry and web site, the Secretary of State shall ensure compliance with state and federal requirements related to patient confidentiality.²³

1-305. Removal of Advance Directive of Deceased Registrant. The Secretary of State shall remove from the Registry the advance directives of deceased registrants. The State Registrar of Vital Statistics shall cooperate with the Secretary of State to identify registrants whose advance directives must be removed from the Registry. The Secretary of State shall remove from the Registry the advance directives of deceased registrants at least once every five (5) years.²⁴

1-306. Secretary of State not Required to Determine Accuracy of Contents of Advance Directives or Validity of Advance Directive; Effect of Registration, Failure to Register and Failure to Notify Secretary of State of

21. *Id.* § 449.925.

22. *Id.* § 449.930.

23. WASH. REV. CODE § 70.02.005 (2011). This section addresses HIPPA concerns. *See generally*, the Health Insurance Portability and Accountability Act of 1996, Pub. L. 104-191, 110 Stat. 1936 (1996) (codified in scattered sections of 42 U.S.C. § 1320d (1996) and 45 C.F.R. §§ 160-164).

24. NEV. REV. STAT. § 449.935.

Revocation of Advance Directive.

1. *The provisions of §1-302 to §1-305, inclusive, do not require the Secretary of State to determine whether the contents of an advance directive submitted for registration are accurate or the execution or issuance of the advance directive complies with the requirements necessary to make the advance directive valid.*
2. *The registration of an advance directive does not establish or create a presumption that the contents of the advance directive are accurate or the execution or issuance of the advance directive complies with the requirements necessary to make the advance directive valid.*
3. *Failure to register and advance directive does not affect the validity of the advance directive.*
4. *Failure to notify the Secretary of State of the revocation of a registrant's advance directive does not affect the validity of the revocation.*²⁵

1-307. Provider of Health Care not Required to Inquire Whether Patient Had Registered Advance Directive or Access Registry; Immunity of Provider of Health Care from Criminal and Civil Liability.

1. *The provisions of §1-301 to §1-306, inclusive, do not require a provider of health care to inquire whether a patient has an advance directive registered on the Registry or to access the Registry to determine the terms of the advance directive.*
2. *A provider of health care who relies in good faith on the provisions of advance directive retrieved from the Registry is immune from criminal and civil liability.*²⁶

1-308. Immunity of Secretary of State and Deputies, Employees and Attorneys of Secretary of State. *Except for acts of gross negligence, willful misconduct, or intentional wrongdoing, the Secretary of State and the deputies, employees and attorneys of the Secretary of State are not subject to civil liability for any claims, demands, actions, or omissions made in good faith by the Secretary of State, deputy, employee or attorney in carrying out the provisions of this act.*²⁷

1-309. Acceptance of Gifts and Grants. *The Secretary of State may charge and collect fees and accept gifts, grants, bequests and other forms of voluntary contributions from any source for the purpose of supporting activities related to the creation and maintenance of the advance directive for health care registry and statewide public education campaigns related to the existence of the registry.*²⁸ *All funds received shall be transferred to the advance directive for health care registry account, created in § 1-301 of this act.*²⁹

1-310. Deposit, Accounting and Use of Money Received; Interest and Income Earned on Money Received; Payment of Claims.

25. *Id.* § 449.940.

26. *Id.* § 449.945.

27. *Id.* § 449.950.

28. *Id.* § 449.955.

29. WASH. REV. CODE § 70.02.005.

1. *All money received by the Secretary of State pursuant to § 1-309 must be;*
 - (a) *Deposited in the State Treasury and accounted for separately in the State General Fund; and*
 - (b) *Used only for the purpose of carrying out the provisions of 1-301, inclusive.*
2. *The Secretary of State shall administer the account. The interest and income earned on the money in the account, after deducting any applicable charges, must be credited to the account.*
3. *The money in the account does not lapse to the State General Fund at the end of any fiscal year.*
4. *Claims against the account must be paid as other claims against the State are paid.*³⁰

1-311. Annual Electronic Message. *The Secretary of State shall send an annual electronic message to individuals that have submitted an advance directive to request that they review the advance directive for health care registry materials to ensure that it is current.*³¹

1-312. Regulations and Rules. *The Secretary of State may adopt regulations and rules as necessary to implement this act.*³²

This proposed legislation accomplishes the goal of providing a central registry and portal for registrants and health care providers to store and access advance directives. The traditional mediums and modalities of creating an advance directive would still exist. The "writing" and "signature" requirements would not be abolished. We would simply digitize existing advance directive documents, and place them in a secure lockbox for easy retrieval, modification, and access when they are most desired and needed.

IV. WHO COULD ADMINISTER AN ADVANCE DIRECTIVE FOR HEALTH CARE REGISTRY?

Which governmental official or agency should be responsible for administration of an advance directive for health care registry? To answer this question we have two models available. In Nevada, the Secretary of State administers the advance directive for health care registry. In Washington and Vermont, the Department of Health administers the state's advance directive for health care registry. There are pros and cons to either choice—Secretary of State, or Department of Health—to administer an

30. NEV. REV. STAT. § 449.960.

31. WASH. REV. CODE § 70.122.130.

32. NEV. REV. STAT. § 449.965.

advance directive for health care registry.

From an administrative standpoint, in most jurisdictions the Secretary of State is a logical choice because the Secretary of State is somewhat accustomed to important filings and other important legal documentation, like business organizational filings and Uniform Commercial Code ("UCC") filings. As it now stands, virtually every Secretary of State's office in the United States maintains an internet website or portal that acts as an interface with members of the general public.³³ The pro to selecting the Secretary of State is that many of these public officials maintain highly developed and efficiently functioning website presence.³⁴ The con is that a number of members of the general public might associate the Secretary of State's office as the place to turn to conduct business, and not as the place to turn to facilitate, convey, and communicate information concerning their health care.

Washington and Vermont have chosen the Department of Health in their respective state to administer the advance directive for health care registry. This is a logical administrative choice—a number of states have a Department of Health or equivalent state agency.³⁵ Simply put, advance

33. In my research, I discovered that forty-seven (47) states have a Secretary of State. *See, e.g.*, <http://www.sos.state.al.us/>; <http://www.azsos.gov/>; <http://sos.state.ar.us/>; <http://www.sos.ca.gov/>; <http://www.sos.state.co.us/>; <http://www.ct.gov/sots/site/default.asp>; <http://sos.delaware.gov/default.shtml>; <http://www.dos.state.fl.us/>; <http://sos.georgia.gov/>; <http://www.sos.idaho.gov/>; <http://www.sos.state.il.us/>; <http://www.in.gov/sos/>; <http://www.sos.state.ia.us/index.html>; <http://www.kssos.org/>; <http://www.sos.ky.gov/>; <http://www.sos.louisiana.gov/>; <http://www.state.me.us/sos/>; <http://www.sos.state.md.us/>; <http://www.sec.state.ma.us/>; <http://www.michigan.gov/sos>; <http://www.sos.state.mn.us/>; <http://www.sos.ms.gov/>; <http://www.sos.mo.gov/>; <http://sos.state.mt.us/>; <http://www.sos.state.ne.us/dyindex.html>; <http://nvsos.gov/>; <http://www.sos.nh.gov/index.html>; <http://www.state.nj.us/state/>; <http://www.sos.state.nm.us/>; <http://www.dos.state.ny.us/>; <http://www.secstate.state.nc.us/>; <http://www.nd.gov/sos/>; <http://www.sos.state.oh.us/sos/>; <https://www.sos.ok.gov/>; <http://www.sos.state.or.us/>; http://www.dos.state.pa.us/portal/server.pt/community/department_of_state/12405; <http://sos.ri.gov/>; <http://www.scsos.com/>; <http://www.sdsos.gov/>; <http://www.state.tn.us/sos/>; <http://www.sos.state.tx.us/>; <http://www.sec.state.vt.us/>; <http://www.commonwealth.virginia.gov/>; <http://www.sos.wa.gov/Default.aspx>; <http://www.sos.wv.gov/Pages/default.aspx>; <http://www.sos.state.wi.us/>; and <http://soswy.state.wy.us/> (all last visited February 15, 2011). The Lieutenant Governor in Alaska, Hawaii, and Utah performs many of the duties and tasks associated with the Secretary of State in other jurisdictions. *See generally*, <http://www.ltgov.state.ak.us/>; <http://hawaii.gov/ltgov>; and <http://www.utah.gov/ltgovernor/> (all last visited February 15, 2011).

34. *See id.*

35. In my research, I discovered that forty-nine (49) states have a Department of Health or equivalent agency. *See, e.g.*, <http://www.adph.org/>; <http://health.hss.state.ak.us/>; <http://www.azdhs.gov/>; <http://www.healthy.arkansas.gov/Pages/default.aspx>; <http://www.cdph.ca.gov/Pages/DEFAULT.aspx>; <http://www.colorado.gov/cs/Satellite/HCPF/HCPF/1197364086675>; <http://www.ct.gov/dph/site/default.asp>; <http://dhss.delaware.gov/dhss/dph/index.html>; <http://www.doh.state.fl.us/>; <http://health.state.ga.us/>; <http://hawaii.gov/health/>; <http://www.healthandwelfare.idaho.gov/>; <http://www.idph.state.il.us/>; <http://www.in.gov/isdh/>; <http://idph.state.ia.us/>; <http://www.kdheks.gov/>; <http://chfs.ky.gov/>; <http://www.dhh.state.la.us/>; <http://www.maine.gov/dhhs/>; <http://www.dhmm.state.md.us/>; <http://www.mass.gov/?pageID=eohhs2homepage&L=1&L0=Home&sid=Eeohhs2>;

directives for health care affect health and well-being, and as such fall under the jurisdiction and purview of the Department of Health. From a subject matter point of view, members of the general public looking to interface with a government official about matters touching upon their health care would be more likely to turn to the Secretary of Health or Commissioner of Health in their state. From a subject matter perspective, this is a major pro. On the other hand, the Department of Health in a particular jurisdiction may not have expertise or a website capable of indexing a large volume of important documentation.

V. HOW WOULD THE WEBSITE OR PORTAL BE CREATED?

In order to create an advance directive for health care registry there are three viable options.³⁶ These options include the following:

1. The Secretary of State or the Department of Health could build the registry in-house using agency staff;³⁷
2. The state could contract with an outside entity to build the registry;³⁸ or
3. The state could contract with an existing and established registry company.³⁹

Nevada, Washington, and Vermont have chosen to contract with U.S. Living Will Registry to build and host their respective websites.⁴⁰ "U.S. Living Will Registry is an established company that has provided registry services to individuals and health care providers across the United States since 1996."⁴¹ Washington used a competitive request for proposal process to choose U.S. Living Will Registry.⁴²

<http://www.michigan.gov/mdch>; <http://www.health.state.mn.us/>;
<http://www.msdl.state.ms.us/>; <http://www.dhss.mo.gov/index.php>;
<http://www.dphhs.mt.gov/>; <http://www.hhs.state.ne.us/>;
<http://www.dhhs.nh.gov/index.htm> <http://www.state.nj.us/health/>;
<http://www.health.state.nm.us/>; <http://www.health.state.ny.us/>; <http://www.ncdhhs.gov/>;
<http://www.ndhealth.gov/>; <http://www.odh.ohio.gov/>; <http://www.ok.gov/health/>;
<http://www.oregon.gov/DHS/index.shtml>;
http://www.portal.state.pa.us/portal/server.pt/community/departement_of_health_home/17457;
<http://www.health.ri.gov/>; <http://www.dhhs.state.sc.us/>; <http://doh.sd.gov/>;
<http://health.state.tn.us/>; <http://www.dshs.state.tx.us/>; <http://health.utah.gov/>;
<http://healthvermont.gov/>; <http://www.vdh.state.va.us/>; <http://www.doh.wa.gov/>;
<http://www.wvdhhr.org/>; <http://www.dhs.wisconsin.gov/>; and <http://wdh.state.wy.us/> (all last visited February 15, 2011).

36. See generally WASHINGTON STATE DEPARTMENT OF HEALTH, LIVING WILL REGISTRY: A REPORT TO THE LEGISLATURE (2009) [hereinafter REPORT] available at <http://www.doh.wa.gov/livingwill/forms/LivingWillRegistry.pdf> (discussing options and matters involved in creating the living will registry).

37. *Id.*

38. *Id.*

39. *Id.*

40. *Id.*

41. *Id.*

42. *Id.*

Thus far, U.S. Living Will Registry has cornered the market for building and hosting state living will registry websites. According to U.S. Living Will Registry:

The U.S. Living Will Registry provides an easy, low-cost, turn key solution for states wishing to start an advance directive and/or organ donor registry. The Registry electronically stores advance directives and organ donor information, and makes them available via secure Internet 24 hours a day. . . .

Utilizing our [U.S. Living Will Registry's] existing time-tested, custom designed system makes setting up a state registry fast and easy. Our sophisticated software can be customized with the look and feel of your state's web pages, and features can be customized to comply with each individual state's statutes and regulations.⁴³

U.S. Living Will Registry website trumpets the cost-savings associated from use of their proprietary software.⁴⁴

Washington quietly launched the living will registry on November 6, 2007.⁴⁵ "Over the next few months, the [Washington Department of Health] solicited feedback from users and stakeholders to improve registry features and marketing messages before announcing the registry publicly."⁴⁶ The Washington living will registry is free to participants.⁴⁷ "Information exchanged with U.S. Living Will Registry is encrypted before transmission using a VeriSign SSL certificate."⁴⁸ The Washington Department of health has gained national exposure as a direct result of the living will registry.⁴⁹ "States such as Minnesota, Alaska, Oregon, Nevada, and West Virginia have all contacted the department [the Washington Department of Health] to request consultation on starting a registry."⁵⁰

VI. WHAT ARE THE COSTS ASSOCIATED WITH CREATING AND MAINTAINING A REGISTRY?

We can look to Washington's experience in creating and maintaining a living will registry to start to discern the costs and expenses associated with

43. *State Registries*, U.S. LIVING WILL REGISTRY, <http://livingwill.uslivingwillregistry.com/state.html> (last visited February 21, 2011).

44. *See id.* (according to U.S. Living Will Registry "[y]our state's tax payers will not have to fund the high costs associated with software design, hardware purchase and ongoing maintenance, not to mention the savings from salaries and benefits for personnel that would be needed to staff the registry.").

45. REPORT, *supra* note 36, at 1.

46. *Id.*

47. *Id.* at 2.

48. *Id.*

49. *Id.*

50. *Id.*

maintaining registry. The Washington State Living Will Registry is funded by the Washington State General Fund.⁵¹ From July 1, 2007, through June 30, 2009, \$363,426 was allocated in the biennial budget for the Washington State Living Will Registry.⁵² Within the Washington Department of Health, the budget allotment funds one staff position.⁵³ "The remainder of the budget primarily funds the registry contract and marketing efforts."⁵⁴

According to the Washington Department of Health, "[a]s of October 2008, the department has spent approximately \$146,000 for registry computer start-up costs and marketing material development."⁵⁵ Through U.S. Living Will Registry, Washington purchased capacity for 3,500 participants.⁵⁶ "This capacity does not expire and can be carried over from year to year until fully used."⁵⁷ According to the Washington Department of Health, "[w]hen all slots are occupied with participants, the cost per participant is approximately \$104."⁵⁸ With increased usage, costs are driven down—creating economies of scale.⁵⁹ Apparently, Washington negotiated a lower cost per participant with increased usage through U.S. Living Will Registry.⁶⁰ "As more space is purchased and occupied, the cost per participant goes down."⁶¹

VII. WHO WOULD POTENTIALLY USE AN ADVANCE DIRECTIVES REGISTRY?

Again, Washington's experience with the Washington Living Will Registry sheds some light on the question of what the potential users might look like demographically. As of October 31, 2008, less than one year after the initial launch of the Washington Living Will Registry, the registry had 347 participants.⁶² The Washington Department of Health indicates that the registry has grown steadily each month with increasing numbers of new participants signing up each month.⁶³ Each month there is an increase in new users or participants.⁶⁴ During the Washington Living Will Registry's first year of existence, September 2008 had the highest increase in new users with 54 new participants signing up.⁶⁵ The Washington Department of Health primarily attributes this steady increase in users to outreach plans to

51. *Id.* at 16.

52. *Id.*

53. *Id.*

54. *Id.*

55. *Id.*

56. *Id.*

57. *Id.*

58. *Id.*

59. *See id.*

60. *See id.*

61. *Id.*

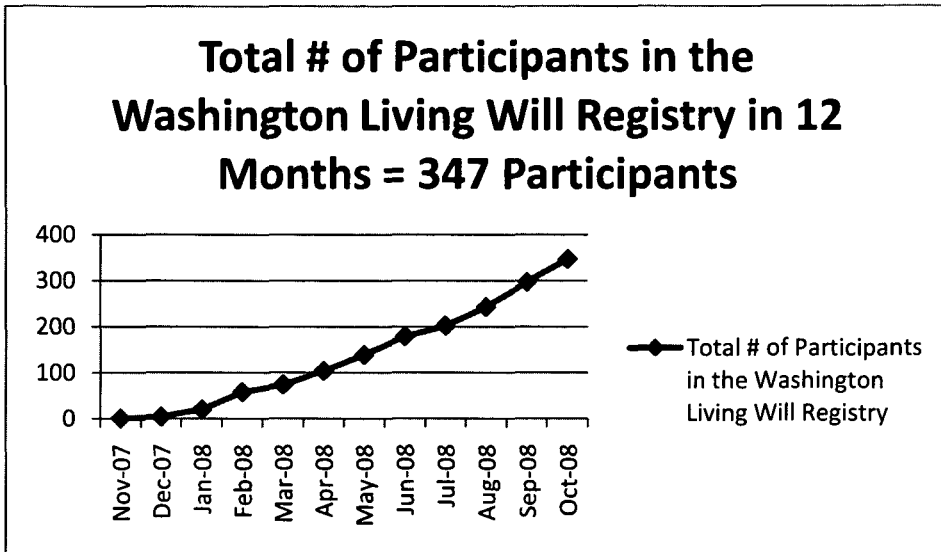
62. *Id.* at 1.

63. *Id.* at 11.

64. *Id.*

65. *Id.* at 12.

educate health care providers.⁶⁶ The Department of Health feels that health care provider education, as a first priority, is yielding dividends in that health care providers are influencing patients and residents and are in turn educating these constituencies about the need to register advance health care directive documents.⁶⁷ Table One displays the total number of participants in the Washington Living Will Registry during the first twelve months.



Nationally, there are very few state-sponsored registries, making it difficult to compare registry start-up data. However, according to U.S. Living Will Registry, which manages registries for Vermont and Nevada, Vermont is having a slow start at getting both residents and health care providers to sign up, and Nevada is having a slow start with getting health care providers signed up.⁶⁸

U.S. Living Will indicates that Washington has the most health care providers signed up and trained to use the registry database system.⁶⁹

Demographically, as of October 31, 2008, sixty percent of Washington Living Will Registry participants were women and forty percent were men. Table Two displays the gender breakdown of Washington Living Will Registry participants.

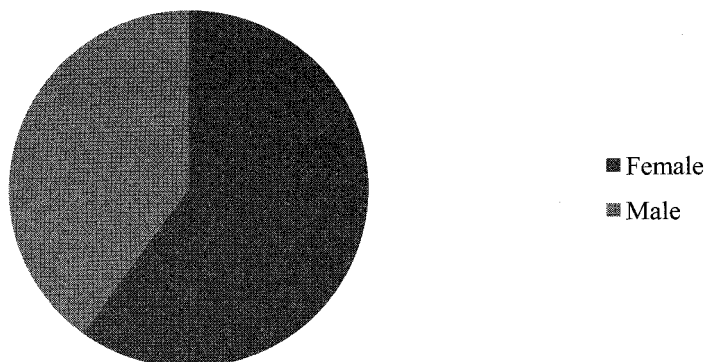
66. *Id.* at 11.

67. *Id.*

68. *Id.*

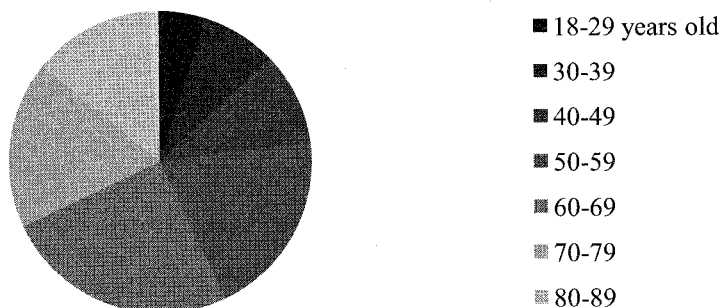
69. *Id.*

Washington Living Will Registry Participant Gender



In terms of age, as of October 31, 2008, the Washington Living Will Registry had participants ranging in age from 18 to 97 years old.⁷⁰ Five percent of the participants in the registry were 18-29 years old, but only one percent of the participants were 90 years old or over.⁷¹ The Washington Living Will Registry appears to be attracting people of all ages.⁷² Table Three, below, shows the age range of participants using the Washington Living Will Registry as of October 31, 2008.

Age of Participants Using the Washington Living Will Registry as of October 31, 2008



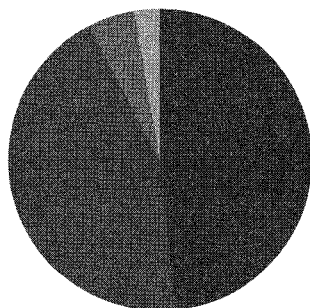
70. *Id.* at 13.

71. *Id.*

72. *Id.*

In Washington, participants can use the Living Will Registry to store health care directives (living wills or advance directives), durable powers of attorney for health care, mental health advance directives, and physician orders for life sustaining treatment ("POLST").⁷³ As of October 31, 2008, there were 717 documents stored in the Washington Living Will Registry.⁷⁴ The month September 2008 saw the submission of 114 new documents alone.⁷⁵ As of October 31, 2008, there were 347 health care directives, 315 durable powers of attorney, 36 physician orders for life sustaining treatment, and 18 mental health advance directives.⁷⁶ Table Four, below, illustrates the type of documents stored on Washington's Living Will Registry.

Type of Documents Stored in the Washington Living Will Registry as of October 31, 2008



- Health Care Directives (347)
- Durable Powers of Attorney (315)
- Physician Orders for Life Sustaining Treatment (36)
- Mental Health Advance Directives (19)

We can learn a great deal from Washington's experience in creating its Living Will Registry. Initially, the number of participants will perhaps be small, but in due course the number of participants will grow. An advance directive registry will be beneficial to from all age brackets and walks of life. Moreover, participants can use the advance directive registry to store a variety of documents, not just living wills. Perhaps, the time has arrived for other states to travel down the road traveled by Nevada, Washington, and Vermont.

73. *Id.* at 4.

74. *Id.* at 14.

75. *Id.*

76. *Id.*

VIII. CONCLUSION

The future for advance directives is now in Nevada, Washington, and Vermont. Nevada, Washington, and Vermont have taken tangible and meaningful steps to "digitize" the previous paper existence of advance directives. We can use the Nevada, Washington, and Vermont experiences with advance directives for health care registries as a model and guiding light. This Article built on Nevada's, Washington's, and Vermont's efforts by providing a model statute that addresses perceived pitfalls and shortcomings in the first attempts to create advance directives for health care registries.

Electronic or digital documents will be a facet of our human lives and experiences for years to come. Electronic or digital portals for advance directives are useful and beneficial in our lives. A time might come when there is a jurisdictional competition to create electronic or digital "friendly" laws that facilitate a citizen's ability to effectively use a web-based portal to store advance directives. Conversely, these jurisdictional competitions will not only benefit citizens, but it will also aid health care providers, who will have easier access to documents that confirm their patient's wishes. In corporate law we acknowledge the jurisdictional competition among states to legislatively create corporate laws conducive to attracting and retaining corporations.⁷⁷ In the future, the legislative landscape might look similar from a jurisdictional competition perspective for states in their race to create advance directive registries or lockboxes that attract citizens to their state keen on taking advantage of the friendliest estate planning laws. Hopefully, this Article will engender and spark the coming legislative competition to create advance directives for health care registries to aid citizens and health care providers alike.

77. See ROBERT HAMILTON, JONATHON MACEY, AND DOUGLAS MOLL, *CASES AND MATERIALS ON CORPORATIONS INCLUDING PARTNERSHIPS AND LIMITED LIABILITY COMPANIES* 137 (11th ed. West 2010) ("The enactment of general and unlimited corporation statutes by New Jersey and other states, followed by Delaware's enactment of its General Corporation Law of 1899, touched off a vigorous jurisdictional competition for corporate charters among the states."). See generally *id.*, at 136-155 (discussing jurisdictional competition in corporate law).

APPENDIX A:**NEVADA STATUTE ESTABLISHING REGISTRY OF ADVANCE DIRECTIVES FOR HEALTH CARE⁷⁸****449.900. Definitions**

As used in NRS 449.900 to 449.965, inclusive, unless the context otherwise requires, the words and terms defined in NRS 449.905, 449.910 and 449.915 have the meanings ascribed to them in those sections.

449.905. "Advance directive" defined

"Advance directive" means an advance directive for health care. The term includes:

1. A declaration governing the withholding or withdrawal of life-sustaining treatment as set forth in NRS 449.535 to 449.690, inclusive;
2. A durable power of attorney for health care as set forth in NRS 162A.700 to 162A.860, inclusive; and
3. A do-not-resuscitate order as defined in NRS 450B.420.

449.910. "Registrant" defined

"Registrant" means a person whose advance directive is registered with the Secretary of State pursuant to NRS 449.925.

449.915. "Registry" defined

"Registry" means the Registry of Advance Directives for Health Care established by the Secretary of State pursuant to NRS 449.920.

449.920. Establishment and maintenance; information to be included in Registry

The Secretary of State shall establish and maintain the Registry of Advance Directives for Health Care on the Internet website of the Secretary of State. The Registry must include, without limitation, in a secure portion of the website, an electronic reproduction of each advance directive. The electronic reproduction must be capable of being viewed on the website and downloaded, printed or otherwise retrieved by a person as set forth in NRS 449.930.

78. NEV. REV. STAT. §§ 449.900 – 449.965 (2010).

449.925. Registration of advance directive: Requirements; duties of Secretary of State

1. A person who wishes to register an advance directive must submit to the Secretary of State:
 - (a) An application in the form prescribed by the Secretary of State;
 - (b) A copy of the advance directive; and
 - (c) The fee, if any, established by the Secretary of State pursuant to NRS 449.955.
2. If the person satisfies the requirements of subsection 1, the Secretary of State shall:
 - (a) Make an electronic reproduction of the advance directive and post it to the Registry;
 - (b) Assign a registration number and password to the registrant; and
 - (c) Provide the registrant with a registration card that includes, without limitation, the name, registration number and password of the registrant.
3. The Secretary of State shall establish procedures for:
 - (a) The registration of an advance directive that replaces an advance directive that is posted on the Registry;
 - (b) The removal from the Registry of an advance directive that has been revoked following the revocation of the advance directive or the death of the registrant; and
 - (c) The issuance of a duplicate registration card or the provision of other access to the registrant's registration number and password if a registration card issued pursuant to this section is lost, stolen, destroyed or otherwise unavailable.

449.930. Access to advance directive

1. Except as otherwise provided in this section, the Secretary of State shall not provide access to a registrant's advance directive unless:
 - (a) The person requesting access provides the registration number and password of the registrant;
 - (b) The Secretary of State determines that providing access to the advance directive is in the best interest of the registrant;
 - (c) Access to the advance directive is required pursuant to the lawful order of a court of competent jurisdiction; or

(d) Access to the advance directive is requested by the registrant or the registrant's personal representative.

2. A registrant or the personal representative of a registrant may access the registrant's advance directive for any purpose. A provider of health care to the registrant may access the registrant's advance directive only in connection with the provision of health care to the registrant.

449.935. Removal of advance directive of deceased registrant

The Secretary of State shall remove from the Registry the advance directives of deceased registrants. The State Registrar of Vital Statistics shall cooperate with the Secretary of State to identify registrants whose advance directives must be removed from the Registry. The Secretary of State shall remove from the Registry the advance directives of deceased registrants at least once every 5 years.

449.940. Secretary of State not required to determine accuracy of contents of advance directive or validity of advance directive; effect of registration, failure to register and failure to notify Secretary of State of revocation of advance directive

1. The provisions of NRS 449.900 to 449.965, inclusive, do not require the Secretary of State to determine whether the contents of an advance directive submitted for registration are accurate or the execution or issuance of the advance directive complies with the requirements necessary to make the advance directive valid.
2. The registration of an advance directive does not establish or create a presumption that the contents of the advance directive are accurate or the execution or issuance of the advance directive complies with the requirements necessary to make the advance directive valid.
3. Failure to register an advance directive does not affect the validity of the advance directive.
4. Failure to notify the Secretary of State of the revocation of a registrant's advance directive does not affect the validity of the revocation.

449.945. Provider of health care not required to inquire whether patient has registered advance directive or access Registry; immunity of provider of health care from criminal and civil liability

1. The provisions of NRS 449.900 to 449.965, inclusive, do not require a provider of health care to inquire whether a patient has an advance directive registered on the Registry or to access the Registry to determine the terms of the advance directive.

2. A provider of health care who relies in good faith on the provisions of an advance directive retrieved from the Registry is immune from criminal and civil liability as set forth in:

- (a) NRS 449.630, if the advance directive is a declaration governing the withholding or withdrawal of life-sustaining treatment executed pursuant to NRS 449.535 to 449.690, inclusive, or a durable power of attorney for health care executed pursuant to NRS 162A.700 to 162A.860, inclusive; or
- (b) NRS 450B.540, if the advance directive is a do-not resuscitate order as defined in NRS 450B.420.

449.950. Immunity of Secretary of State and deputies, employees and attorneys of Secretary of State

The Secretary of State and the deputies, employees and attorneys of the Secretary of State are not liable for any action or omission made in good faith by the Secretary of State, deputy, employee or attorney in carrying out the provisions of NRS 449.900 to 449.965, inclusive.

449.955. Suspension of components of Registry and duties of Secretary of State if sufficient money not available; fees authorized; acceptance of gifts and grants

1. On or before July 1 of each odd-numbered year, the Secretary of State shall make a determination of whether sufficient money is available and authorized for expenditure to fund one or more components of the programs and other duties of the Secretary of State relating to NRS 449.900 to 449.965, inclusive.
2. The Secretary of State shall temporarily suspend any components of the programs or duties of the Secretary of State for which he or she determines pursuant to subsection 1 that sufficient money is not available.
3. The Secretary of State may charge and collect fees and accept gifts, grants, bequests and other contributions from any source for the purpose of carrying out the provisions of NRS 449.900 to 449.965, inclusive.

449.960. Deposit, accounting and use of money received; interest and income earned on money received; payment of claims

1. All money received by the Secretary of State pursuant to NRS 449.900 to 449.965, inclusive, must be:
 - (a) Deposited in the State Treasury and accounted for separately in the State General Fund; and

(b) Used only for the purpose of carrying out the provisions of NRS 449.900 to 449.965, inclusive.

2. The Secretary of State shall administer the account. The interest and income earned on the money in the account, after deducting any applicable charges, must be credited to the account.
3. The money in the account does not lapse to the State General Fund at the end of any fiscal year.
4. Claims against the account must be paid as other claims against the State are paid.

449.965. Regulations

The Secretary of State may adopt regulations to carry out the provisions of NRS 449.900 to 449.965, inclusive.

APPENDIX B:**WASHINGTON "NATURAL DEATH ACT" ESTABLISHING THE WASHINGTON LIVING WILL REGISTRY⁷⁹****70.122.020. Definitions**

Unless the context clearly requires otherwise, the definitions contained in this section shall apply throughout this chapter.

- (1) "Adult person" means a person who has attained the age of majority as defined in RCW 26.28.010 and 26.28.015, and who has the capacity to make health care decisions.
- (2) "Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.
- (3) "Directive" means a written document voluntarily executed by the declarer generally consistent with the guidelines of RCW 70.122.030.
- (4) "Health facility" means a hospital as defined in *RCW 70.41.020(2) or a nursing home as defined in RCW 18.51.010, a home health agency or hospice agency as defined in RCW 70.126.010, or a boarding home as defined in RCW 18.20.020.
- (5) "Life-sustaining treatment" means any medical or surgical intervention that uses mechanical or other artificial means, including artificially provided nutrition and hydration, to sustain, restore, or replace a vital function, which, when applied to a qualified patient, would serve only to prolong the process of dying. "Life-sustaining treatment" shall not include the administration of medication or the performance of any medical or surgical intervention deemed necessary solely to alleviate pain.
- (6) "Permanent unconscious condition" means an incurable and irreversible condition in which the patient is medically assessed within reasonable medical judgment as having no reasonable probability of recovery from an irreversible coma or a persistent vegetative state.
- (7) "Physician" means a person licensed under chapters 18.71 or 18.57 RCW.
- (8) "Qualified patient" means an adult person who is a patient diagnosed in writing to have a terminal condition by the patient's attending physician, who has personally examined the patient, or a patient who is diagnosed in writing to be in a permanent unconscious condition in accordance with accepted medical standards by two physicians, one of whom is the patient's attending physician, and both of whom have personally examined the patient.

79. R.C.W §§ 70.122.120 - 70.122.140 (2011).

(9) "Terminal condition" means an incurable and irreversible condition caused by injury, disease, or illness, that, within reasonable medical judgment, will cause death within a reasonable period of time in accordance with accepted medical standards, and where the application of life-sustaining treatment serves only to prolong the process of dying.

70.122.030. Directive to withhold or withdraw life-sustaining treatment

(1) Any adult person may execute a directive directing the withholding or withdrawal of life-sustaining treatment in a terminal condition or permanent unconscious condition. The directive shall be signed by the declarer in the presence of two witnesses not related to the declarer by blood or marriage and who would not be entitled to any portion of the estate of the declarer upon declarer's decease under any will of the declarer or codicil thereto then existing or, at the time of the directive, by operation of law then existing. In addition, a witness to a directive shall not be the attending physician, an employee of the attending physician or a health facility in which the declarer is a patient, or any person who has a claim against any portion of the estate of the declarer upon declarer's decease at the time of the execution of the directive. The directive, or a copy thereof, shall be made part of the patient's medical records retained by the attending physician, a copy of which shall be forwarded by the custodian of the records to the health facility when the withholding or withdrawal of life-support treatment is contemplated. The directive may be in the following form, but in addition may include other specific directions:

Health Care Directive

Directive made this day of (month, year).

I, having the capacity to make health care decisions, willfully, and voluntarily make known my desire that my dying shall not be artificially prolonged under the circumstances set forth below, and do hereby declare that:

(a) If at any time I should be diagnosed in writing to be in a terminal condition by the attending physician, or in a permanent unconscious condition by two physicians, and where the application of life-sustaining treatment would serve only to artificially prolong the process of my dying, I direct that such treatment be withheld or withdrawn, and that I be permitted to die naturally. I understand by using this form that a terminal condition means an incurable and irreversible condition caused by injury, disease, or illness, that would within reasonable medical judgment cause death within a reasonable period of time in accordance with accepted medical standards, and where the application of life-sustaining treatment would serve only to prolong the process of dying. I further understand in using this form that a permanent unconscious condition means an incurable and irreversible condition in which I am medically assessed

within reasonable medical judgment as having no reasonable probability of recovery from an irreversible coma or a persistent vegetative state.

(b) In the absence of my ability to give directions regarding the use of such life-sustaining treatment, it is my intention that this directive shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and I accept the consequences of such refusal. If another person is appointed to make these decisions for me, whether through a durable power of attorney or otherwise, I request that the person be guided by this directive and any other clear expressions of my desires.

(c) If I am diagnosed to be in a terminal condition or in a permanent unconscious condition (check one):

I DO want to have artificially provided nutrition and hydration.

I DO NOT want to have artificially provided nutrition and hydration.

(d) If I have been diagnosed as pregnant and that diagnosis is known to my physician, this directive shall have no force or effect during the course of my pregnancy.

(e) I understand the full import of this directive and I am emotionally and mentally capable to make the health care decisions contained in this directive.

(f) I understand that before I sign this directive, I can add to or delete from or otherwise change the wording of this directive and that I may add to or delete from this directive at any time and that any changes shall be consistent with Washington state law or federal constitutional law to be legally valid.

(g) It is my wish that every part of this directive be fully implemented. If for any reason any part is held invalid it is my wish that the remainder of my directive be implemented.

Signed.

City, County, and State of Residence

The declarer has been personally known to me and I believe him or her to be capable of making health care decisions.

Witness.

Witness.

(2) Prior to withholding or withdrawing life-sustaining treatment, the diagnosis of a terminal condition by the attending physician or the diagnosis of a permanent unconscious state by two physicians shall be entered in writing and made a permanent part of the patient's medical records.

(3) A directive executed in another political jurisdiction is valid to the extent permitted by Washington state law and federal constitutional law.

70.122.040. Revocation of directive

(1) A directive may be revoked at any time by the declarer, without regard to the declarer's mental state or competency, by any of the following methods:

(a) By being canceled, defaced, obliterated, burned, torn, or otherwise destroyed by the declarer or by some person in the declarer's presence and by the declarer's direction.

(b) By a written revocation of the declarer expressing his or her intent to revoke, signed, and dated by the declarer. Such revocation shall become effective only upon communication to the attending physician by the declarer or by a person acting on behalf of the declarer. The attending physician shall record in the patient's medical record the time and date when the physician received notification of the written revocation.

(c) By a verbal expression by the declarer of his or her intent to revoke the directive. Such revocation shall become effective only upon communication to the attending physician by the declarer or by a person acting on behalf of the declarer. The attending physician shall record in the patient's medical record the time, date, and place of the revocation and the time, date, and place, if different, of when the physician received notification of the revocation.

(d) In the case of a directive that is stored in the health care declarations registry under RCW 70.122.130, by an online method established by the department of health. Failure to use this method of revocation for a directive that is stored in the registry does not invalidate a revocation that is made by another method described under this section.

(2) There shall be no criminal or civil liability on the part of any person for failure to act upon a revocation made pursuant to this section unless that person has actual or constructive knowledge of the revocation except as provided in RCW 70.122.051(4).

(3) If the declarer becomes comatose or is rendered incapable of communicating with the attending physician, the directive shall remain in effect for the duration of the comatose condition or until such time as the declarer's condition renders the declarer able to communicate with the attending physician.